The National Elder Abuse Incidence Study

Executive Summary

Introduction and Background

America's burgeoning elder population has affected every segment of the social, political, and economic landscape. Public debate of the issues surrounding the special needs of the approximately 44 million persons in this country age 60 years and over has heightened national awareness and concern. As a result, public policies relating to issues such as retirement security, affordable long-term care, and quality of life are changing to meet the unique needs of the aging population. Yet, as the public looks toward improving the lives of the elderly, abuse and neglect of elders living in their own homes have gone largely unidentified and unnoticed. The National Elder Abuse Incidence Study has shed new light on this significant problem with the finding that approximately 450,000 elderly persons in domestic settings were abused and/or neglected during 1996. When elderly persons who experienced self-neglect are added, the number increases to approximately 551,000 in 1996. Additionally, through this study we have learned that:

- Female elders are abused at a higher rate than males, after accounting for their larger proportion in the aging population.
- Our oldest elders (80 years and over) are abused and neglected at two to three times their proportion of the elderly population.
- In almost 90 percent of the elder abuse and neglect incidents with a known perpetrator, the perpetrator is a family member, and two-thirds of the perpetrators are adult children or spouses.
- Victims of self-neglect are usually depressed, confused, or extremely frail.

The National Elder Abuse Incidence Study (NEAIS) was conducted by the National Center on Elder Abuse at the American Public Human Services Association (formally known as the American Public Welfare Association) and the Maryland-based social science and survey research firm, Westat. The Administration for Children and Families (ACF) and the Administration on Aging (AoA) in the U.S. Department of Health and Human Services jointly funded this research. The study asked the fundamental

question: What is the incidence of domestic elder abuse and neglect in the United States today? In public health and social research, the term "incidence" means the number of new cases occurring over a specific time period. The NEAIS used a rigorous methodology to collect national incidence data on what has been a largely undocumented phenomenon, and it provides the basis to estimate the incidence of domestic elder abuse and neglect among those aged 60 and above in 1996.

The NEAIS originated in 1992 when Congress, through the Family Violence Prevention and Services Act of 1992 (P.L. 102-295), directed that a study of the national incidence of abuse, neglect, and exploitation of elderly persons be conducted under the auspices of the Administration for Children and Families. ACF consulted with the federal Administration on Aging, resulting in the two agencies combining resources and expertise to support the national study. Because the legislative mandate primarily was concerned with the prevention of violence in domestic settings, the study focused only on the maltreatment of non-institutionalized elderly. Elders living in hospitals, nursing homes, assisted-living facilities, or other institutional or group facilities were not included in the study.

In order to maximize the utility of the research, the study also collected and analyzed data about elder self-neglect in domestic settings, and these findings are reported separately from the findings for abuse and neglect. In the NEAIS, the phrase "elder maltreatment" generally refers to the seven types of abuse and neglect that are measured in the study—physical abuse, sexual abuse, emotional or psychological abuse, financial or material exploitation, abandonment, neglect, and self-neglect. An early task of the NEAIS was to develop standardized definitions for each specific type of abuse and neglect, which are provided later in this executive summary.

Prior attempts to generate national data on domestic elder abuse in the United States relied on state-compiled statistics of suspected abuse, with considerable variations in definitions and comprehensiveness of reporting systems. These earlier studies, frequently designed to estimate the prevalence (i.e., the total number of cases at a designated time period) of elder abuse rather than the incidence (i.e., the new cases occurring over a specific period of time), varied considerably in their research questions, methodology, sources of data, analysis, and findings. Accordingly, comparisons of earlier research with the NEAIS findings should be done cautiously.

The NEAIS gathered data on domestic elder abuse, neglect, and self-neglect through a nationally representative sample of 20 counties in 15 states. For each county sampled, the study collected data from two sources: (1) reports from the local Adult Protective Services (APS) agency responsible for receiving and investigating reports in each county: and (2) reports from "sentinels"—specially trained individuals in a variety of community agencies having frequent contact with the elderly. The NEAIS study design and methods are described more fully later in this Executive Summary.

The NEAIS research is groundbreaking because it provides, for the first time, national incidence estimates of elder abuse, which can serve as a baseline for future research and service interventions in this critical problem. Its findings confirm some commonly held theories about elder abuse and neglect, notably that officially reported cases of abuse are only the "tip of the iceberg," or a partial measure of a much larger, unidentified problem. The NEAIS final report offers insight into critical questions, including: who are the victims of elder abuse and neglect, and who are the perpetrators? Who are the reporters of abuse and neglect? What are the characteristics of self-neglecting elders? What is the extent of the problem of abuse, neglect, and self-neglect in our communities and what forms do they take?

National Elder Abuse Incidence Estimates

To arrive at the most accurate estimate of the national incidence of elder abuse and neglect in 1996, researchers added two numbers: (1) reports submitted to APS agencies and substantiated (i.e., determined to have occurred or be occurring) by those agencies, and (2) reports made by sentinels and presumed to be substantiated. Consistent with three national incidence studies on child abuse and neglect, this methodology assumes the sentinel reports represent substantiated reports. Because the incidence estimate is statistically derived from the nationally representative sample, researchers also calculated the standard error to establish the range of the incidence estimate within a 95 percent confidence interval. ¹

Using the identical methodology, researchers also separately calculated the estimated national incidence of elder abuse, neglect, <u>and/or self-neglect</u> in 1996. Both incidence estimates are for unduplicated elderly persons. In other words, individuals are counted only once, even if: (1) they were

The standard error of the estimates of APS agencies is relatively low because of the large number of actual reports (1,466) by those agencies in the sample, while the standard error for the sentinel data is relatively large because of the smaller number of reports (140) in the study sample. The range of the "true" value, at the 95 percent confidence level, for an estimated number is plus and minus two times the standard error.

abused and neglected and/or self-neglecting, (2) more than one report were received about the same incident, or (3) different incidents were reported for the same elderly person during the study period.

Estimated Incidence of Elder Abuse and/or Neglect in 1996

The best national estimate is that a total of 449,924 elderly persons, aged 60 and over, experienced abuse and/or neglect in domestic settings in 1996. Of this total, 70,942 (16 percent) were reported to and substantiated by APS agencies, but the remaining 378,982 (84 percent) were not reported to APS. From these figures, one can conclude that over five times as many new incidents of abuse and neglect were unreported than those that were reported to and substantiated by APS agencies in 1996. The standard error suggests that nationwide as many as 688,948 elders or as few as 210,900 elders could have been victims of abuse and/or neglect in domestic settings in 1996.

Elder Abuse, Neglect, and/or Self-Neglect in 1996

The best national estimate is that a total of 551,011 elderly persons, aged 60 and over, experienced abuse, neglect, and/or self-neglect in domestic settings in 1996. Of this total, 115,110 (21 percent) were reported to and substantiated by APS agencies, with the remaining 435,901 (79 percent) not being reported to APS agencies. One can conclude from these figures that almost four times as many new incidents of elder abuse, neglect, and/or self-neglect were unreported than those that were reported to and substantiated by APS agencies in 1996. The standard error suggests that nationwide as many as 787,027 elders or as few as 314,995 elders could have been abused, neglected, and/or self-neglecting in domestic settings in 1996.

Abuse and Neglect Reported by APS Agencies

Characteristics of Victims of Domestic Elder Abuse

Of 236,479 reports of abuse, neglect, and self-neglect to APS in 1996, 48.7 percent, or 115,110 reports were **substantiated after investigation**, 39.3 percent were unsubstantiated, and 8.2 percent were still under investigation at the end of 1996. The remaining 3.8 percent of reports had other outcomes (e.g., suspected victim died, could not be located, or had moved away).

Of the 115,110 substantiated reports in 1996 for which information was available, 61.6 percent (70,942) were reports of incidents in which elders were maltreated by other people (also called "perpetrators"), while the remaining 38.4 percent (44,168) were incidents of self-neglecting elders. Of the 70,942 unduplicated substantiated reports of elder abuse attributable to perpetrators (which excludes self-neglect), the most common types were: neglect (34,525), emotional/ psychological abuse (25,142), financial/material exploitation (21,427), and physical abuse (18,144).

While the substantiation rate for all types of investigations of elder abuse combined was 48.7 percent, the **substantiation rates for different types of maltreatment** varied considerably, as follows: physical abuse—61.9 percent; abandonment—56.0 percent; emotional/psychological abuse—54.1 percent; financial/material abuse—44.5 percent; and neglect—41.0 percent. (The substantiation rate for sexual abuse was not statistically significant.)

A wide variety of **reporters of domestic elder abuse** were found in the 70,942 substantiated reports of abuse and neglect. The most frequent reporters were family members, who were responsible for 20.0 percent of all reports, followed by hospitals (17.3 percent), and police and sheriffs (11.3 percent). In-home service providers, friends/neighbors, and physician/nurses/clinics each reported between 8 and 10 percent of total reports. The remaining reports were made by out-of-home service providers, banks, public health departments, and other reporters.

Hospitals (19.8 percent) and friends/neighbors (19.1 percent) were the most frequent **reporters of substantiated reports of self-neglect** in 1996. Police/sheriff, in-home service providers, and physicians/nurses/clinics each reported 12 percent of total reports. Out-of-home providers, family members, banks, the victims themselves, and other reporters made the remaining reports.

The report examines the **age of victims** of different types of abuse reported to APS. The oldest elders (those over 80 years of age), who made up about 19 percent of the U.S. elderly population in 1996, were far more likely to be the victims of all categories of abuse, with the exception of abandonment. They accounted for over half the reports of neglect (51.8 percent), and 48.0 percent of financial/material abuse, 43.7 percent of physical abuse, and 41.3 percent of emotional/psychological abuse. In all types of abuse and neglect, elderly victims in the 60–64 and 65–69 age groups accounted for the smallest percentages.

Female elders were more likely to be the victims of all categories of abuse, except for abandonment. While making up about 58 percent of the total national elderly population in 1996, women were the victims in 76.3 percent of emotional/psychological abuse, 71.4 percent of physical abuse, 63.0 percent of financial/material exploitation, and 60.0 percent of neglect, which was the most frequent type of maltreatment. A majority of the victims of abandonment were men (62.2 percent).

In 1996, **white elders** were 84.0 percent of the total elder population, while black elders comprised 8.3 percent, and Hispanic elders were 5.1 percent. While white elders were the victims in eight out of ten reports for most types of maltreatment, black elders were over-represented in neglect (17.2 percent), financial/material exploitation (15.4 percent), and emotional/psychological abuse (14.1 percent). Hispanic elders and those from other racial/ethnic groups were under-represented among victims in all types of maltreatment.

The study found that elders who are **unable to care for themselves** were more likely to suffer from abuse. Approximately one-half (47.9 percent) of the substantiated incidents of elder abuse involved elderly persons who were not able to care for themselves, 28.7 percent were somewhat able to do so, and 22.9 percent were able to care for themselves. For the national elderly population as a whole, the federal government estimates that 14 percent have difficulties with one or more activities of daily living.²

Approximately six out of ten substantiated elder abuse victims experienced some degree of **confusion** (31.6 percent were very confused, or disoriented, and 27.9 percent were sometimes confused). This represents a high degree of potential mental impairment among this group of abused elders, particularly when compared with the estimated 10 percent of the total national elderly population suffering with some form of dementia.

² Nov. 1997 U.S. Census Bureau report on disability status of persons 65 years and older in 1994-95.

About 44 percent of all substantiated abused elders were gauged to be **depressed** at some level, with about 6 percent of them severely depressed. This compares with the estimated 15 percent of all elders nationally who are depressed at any one time. One-third of substantiated elder abuse victims (35.4 percent) displayed no signs of depression.

Characteristics of Perpetrators of Domestic Elder Abuse

Overall, men were the perpetrators of abuse and neglect 52.5 percent of the time. Of the substantiated cases of abuse and neglect, **males were the most frequent perpetrators** for abandonment (83.4 percent), physical abuse (62.6 percent), emotional abuse (60.1 percent) and financial/material exploitation (59.0 percent). Only in cases of neglect were women slightly more frequent (52.4 percent) perpetrators than men.

The **age category** with the most perpetrators was the 41 to 59 age group (38.4 percent), followed by those in the 40 years or less group who were perpetrators in more than one quarter of reports (27.4 percent). About one-third of perpetrators (34.3 percent) were elderly persons themselves (60 and over). Perpetrators of financial/material exploitation were particularly younger compared to other types of abuse, with 45.1 percent being 40 or younger and another 39.5 percent being 41–59 years old. Eighty-five percent of the perpetrators of financial/material exploitation were under age 60.

About three-fourths (77.4 percent) of domestic elder abuse perpetrators in 1996 were white, and less than one-fifth (17.9 percent) were black. Other minority groups accounted for only 2 percent of the perpetrators, while the race of 2.7 percent of perpetrators was unknown.

Data show that **family members** were the perpetrators in nine out of ten (89.7 percent) substantiated incidents of domestic elder abuse and neglect. Adult children of elder abuse victims were the most likely perpetrators of substantiated maltreatment (47.3 percent). Spouses represented the second largest group of perpetrators (19.3 percent). In addition, other relatives and grandchildren, at 8.8 percent and 8.6 percent respectively, were the next largest groups of perpetrators. Non-family perpetrators included friends/neighbors (6.2 percent), in-home service providers (2.8 percent), and out-of home service providers (1.4 percent). The report provides details about the relationship of perpetrators to the victims for the different types of maltreatment.

Characteristics of Self-Neglecting Elders

Self-neglect was included in the NEAIS and a common definition and signs and symptoms were adopted for it, as with all the specific types of abuse and neglect. Self-neglect is characterized as the behaviors of an elderly person that threaten his/her own health or safety. Self-neglect generally manifests itself in an older person's refusal or failure to provide himself or herself with adequate food, water, clothing, shelter, safety, personal hygiene, and medication (when indicated).³

Approximately two-thirds (65.3 percent) of substantiated self-neglecting elders were female, compared with women being 58 percent of the overall elderly population. About two-thirds (65.1 percent) of self-neglecting elders were 75 years or older (or almost twice their proportion of the overall elderly). The largest proportion of self-neglecting elders were in the oldest age category of 80 and over (44.7 percent), while the proportion decreased in each declining age group, with only 6.3 percent of self-neglecting elders being in the 60–64 year age group (compared to their being 23 percent of the total elderly population).

Self-neglecting elders were predominately white (77.4 percent), while 20.9 percent were black and 1.7 percent were other or unknown. The black elderly are two-and-a-half times more likely to be self-neglecting than their proportion of the elderly population.

Not surprisingly, most (93.3 percent) self-neglecting elders have difficulty caring for themselves. Of these elders, 34.3 percent are not capable of caring for themselves, while 59.0 percent are somewhat able to care for themselves. Three out of ten self-neglecting elders (29.9 percent) are very confused or disoriented, while 45.4 percent are sometimes confused. Three-quarters (75.3 percent) of substantiated self-neglecting elders suffer from some degree of confusion.

Abuse and Neglect Reported by Sentinel Agencies

The remaining findings from the NEAIS address elder abuse reported by 1,156 sentinel reporters in the 248 sentinel agencies. Since sentinel data are not officially reported to the APS agencies, they are not officially substantiated. Sentinels were, however, carefully trained to screen out incidents

³ For purposes of this study, the definition of "self-neglect" excludes a situation in which a mentally competent older person (who understands the consequences of her/his decisions) makes a conscious and voluntary decision to engage in acts that threaten her/his health or safety.

that would not be supported. The unduplicated sentinel reports were relatively small in number (140) and, therefore, standard errors are relatively high.

Characteristics of Elderly Victims of Nonreported Domestic Abuse and Neglect (Sentinel)

Neglect was highest among those 80 years and over (60.0 percent). Physical, emotional, and financial abuse were found at higher rates among those aged 60 to 70 than among those 80 and older.

As with APS reports, a majority of victims of all types of abuse were women, as reported by sentinels. Although women represented about 58 percent of the total U.S. elderly population in 1996, over 80 percent of the physical abuse recognized by sentinels, over 90 percent of the financial abuse, over 70 percent of the emotional abuse, and over 65 percent of the neglect cases was found among women rather than men. Abandonment was also more frequent for women (65.4 percent), in contrast to substantiated APS reports, which show men were more likely to be abandoned (62.2 percent).

The data do not show that rates of unreported abuse and neglect are higher among minorities than among nonminorities. Rather, minorities, which collectively accounted for 15.5 percent of the total elderly population in 1996, were victims of abuse, as reported by sentinels, between 3.6 and 7.6 percent depending on the type of abuse.

Data from sentinel reports reveal that only one-third (33.8 percent) of the victims were **able to care for themselves**, another one-third (33.1 percent) were somewhat able to care for themselves, and 18.8 percent were not able to care for themselves. (Sentinels were unable to make a determination 14.2 percent of the time.) Individuals experiencing neglect, abandonment, and self-neglect were most often reported by sentinels as not able or only somewhat able to care for themselves. Two-thirds (67.7 percent) of those that were physically abused were thought to have the ability to care for themselves, suggesting that such abuse is not perpetrated on just the most vulnerable individuals.

Sentinels reported, through observation not diagnosis, that over one-third (36.6 percent) of alleged victims were not **confused**, about an equal proportion (37.9 percent) were sometimes confused, and a relatively small percentage (7.5 percent) were very confused or disoriented. Sentinels were unable

to make one of these choices 18.0 percent of the time. Confusion was most common among those who experienced neglect, abandonment, and self-neglect.

In noting observations of **depression,** sentinels were unable to make a determination for a third of the elders they saw. Sentinel data show that 20.0 percent of the alleged victims were not depressed, 41.4 percent seemed to be moderately depressed, and a relatively small proportion (5.5 percent) appeared severely depressed. Signs and symptoms of moderate or severe depression were relatively high across all forms of abuse and neglect, but did not stand out for any one category when standard errors are taken into account.

Characteristics of Perpetrators of Nonreported Abuse and Neglect (Sentinel)

As with APS reports, perpetrators reported by sentinels were most frequently **family members** (89.6 percent), including the adult children (30.8 percent), spouses (30.3 percent), and a parent (24.0 percent). Parents are possible abusers of elders because elders were defined as persons aged 60 and over, and some persons in their 60s and 70s had parents in their late 70s and 80s.

Friends, neighbors, and service providers were believed to be responsible for the abuse and neglect 10 percent of the time.

The most common age range for perpetrators was the middle years, ages 36 to 59 (45.5 percent), with 28.6 percent of abuse being committed by people 60 and older, and 15.3 percent by those 35 and younger.

Nearly twice as many men as women were reported as perpetrators of abuse and neglect by sentinels (63.1 percent compared to 35.4 percent).

NEAIS Study Design and Methods

The National Elder Abuse Incidence Study gathered data on domestic elder abuse, neglect, and self-neglect through a nationally representative sample of 20 counties. For each county sampled, the study collected data from two sources: (1) reports from the local Adult Protective Service (APS) agency

responsible for receiving and investigating reports in each county; and (2) reports from approximately 1,100 "sentinels"—specially trained individuals in a variety of community agencies having frequent contact with the elderly. Many sentinels were mandatory or voluntary reporters of elder abuse, as defined by state laws. The sentinel approach to collecting data is an alternative to more costly general population surveys and has been used successfully in all three National Incidence Studies of Child Abuse commissioned by the federal government. This method was pioneered nearly 20 years ago by Westat, APHSA's collaborative partner for the NEAIS study, in the nation's first-ever incidence study on child abuse. The approach is based upon the hypothesis that officially reported cases of abuse represent only a small proportion of actual episodes of abuse in the community.

Establishing Definitions

Historically, a major impediment to collecting uniform data on elder maltreatment nationally has been a lack of comparability of definitions of abuse, neglect, and exploitation. In addition to differences among states, recognized elder experts themselves continue to disagree on definitions. Accordingly, the first task of NEAIS was to develop standardized definitions of elder maltreatment, thus ensuring greater comparability and reliability of results. The process involved several steps:

- <u>Analysis of Current State Definitions</u>—The existing state laws defining abuse, neglect, and exploitation were compiled and analyzed for all states and territories, and the most common components of the definitions across states were selected as potential definitions.
- <u>Convening of Local Roundtables</u>—Two roundtables of representative local professionals who deal with elder abuse, neglect, and exploitation were convened to obtain firsthand, community-level information on how elder abuse is detected, reported, and investigated, which aided in the development of the standardized definitions.
- Consensus Meeting—A group of elder abuse experts and researchers, including NCEA and NEAIS advisory committee members, provided an in-depth analysis of the draft definitions and revised and prepared them for pilot-testing. The final definitions included:
 - **Physical abuse** was defined as the use of physical force that may result in bodily injury, physical pain, or impairment. Physical punishments of any kind were examples of physical abuse.
 - **Sexual abuse** was defined as non-consensual sexual contact of any kind with an elderly person.
 - **Emotional or psychological abuse** was defined as the infliction of anguish, pain, or distress.

- **Financial or material exploitation** was defined as the illegal or improper use of an elder's funds, property, or assets.
- Abandonment was defined as the desertion of an elderly person by an
 individual who had physical custody or otherwise had assumed responsibility
 for providing care for an elder or by a person with physical custody of an
 elder.
- **Neglect** was defined as the refusal or failure to fulfill any part of a person's obligations or duties to an elder.
- **Self-neglect** was characterized as the behaviors of an elderly person that threaten his/her own health or safety. The definition of self-neglect <u>excludes</u> a situation in which a mentally competent older person (who understands the consequences of his/her decisions) makes a conscious and voluntary decision to engage in acts that threaten his/her health or safety.
- <u>Pilot-Testing</u>—Two Adult Protective Services agencies and seven local sentinel agencies (in the Washington, D.C., area, but not involved in the study) field pilot-tested the definitions and data collection instruments, which were revised based on the results of the tests. (The full definition and signs and symptoms for each type of abuse and neglect are provided in detail in the full report.)

Sampling Counties and Evaluation of Sample

NEAIS employed a stratified, multistage sample of 20 nationally representative counties, selected with probability proportional to the number of elders living in these areas. The counties were stratified by five variables: geographic region, metropolitan area, elder abuse reporting requirements (mandatory and nonmandatory), percentage of elders, and percentage of poor elders. The use of the probability proportional to size method ensures an approximately self-weighting sample—that is, every abused elder in the county has approximately the same chance of being identified, regardless of location, when the measure of size is the number of elders in the county. This methodology produced a sample of 20 counties in 15 states, with five counties in each of the four major geographic regions of the country. The sample also was reflective of the other four stratification variables.

Because the sample was based on 20 out of about 3,000 counties in the country, it was important to examine the accuracy of the elder abuse estimates using outside sources, to the extent possible. The National Center on Elder Abuse (NCEA), in spring 1997, conducted *A Survey of State APS and Aging Agencies on Domestic Abuse for FY 95 and 96*. All states shared counts of all domestic elder abuse reports to state report-receiving agencies and these data were compiled to be comparable to that

collected by the NEAIS. Using rigorous estimation methods, data were weighted to represent national totals and annualized. The numbers of cases in the data obtained from the states by NCEA were very close to the NEAIS national estimates. The total number of actual reports obtained from the states by NCEA was only 1.4 percent greater than the NEAIS estimated total. The statistical procedures used to produce the national estimates in this NEAIS appear to be extremely accurate.

Sampling Sentinel Agencies and Sentinels

One of the most important elements of the NEAIS was the selection of four types of community agencies from which community sentinels would be selected: <u>law enforcement agencies</u> (sheriff's departments and municipal police departments); <u>hospitals</u> (including public health departments); <u>elder care providers</u> (adult day care centers, senior centers, and home health care agencies); <u>financial institutions</u> (banks). Using the best sources of agency listings for each sentinel type, a sample was drawn for each of the 20 sampled counties, usually averaging 12–13 agencies per county. Two banks per county were selected to ensure that possible incidents of financial exploitation of elders would be identified. The remaining agencies were distributed among the other categories of agencies proportional to the number of agencies available in each county, resulting in a total of 248 sentinel agencies in the 20 counties participating in the study.

A rigorous methodology was used to select the actual sentinels within the designated sentinel agencies. To be eligible, individuals had to have frequent contact with the elderly and had to be able to identify abuse if they encountered it. A computer software program was used to randomly pick every *nth* sentinel from a roster of eligible sentinel candidates provided by the agency. The number of sentinels selected per agency was typically four to six, with a total of about 50 sentinels per county. This resulted in a total of 1,158 sentinels participating in the study across the 20 counties.

The designation of Adult Protective Services (APS) agencies, on the other hand, is made by each state, and the designated agency varies by state. For the 20 sampled counties, the distribution of APS agencies participating in the study were: 10 in the state human services agency; six in the state unit on aging, but within the human services agency; and four in the state unit on aging and outside the human services agency.

Data Forms and Training

The data collection forms for both the APS caseworkers and sentinel agency staff were designed to be easy to complete and to require as few references as possible to other documents. As with the abuse and neglect definitions, several versions of the instruments were extensively pilot-tested with local APS and service agency staff. The APS and sentinel data forms were identical with two exceptions: the APS instrument included sections for documenting the source of the report to the agency and for the disposition of the case following investigation (i.e., substantiated or unsubstantiated), while the sentinel forms did not.

In order to increase valid and reliable reporting across all 20 counties, an innovative approach was developed for training sentinels and APS agency personnel using a specially designed participant guide book and instructional videos. The training focused on identifying elder abuse according to the standardized definitions and related signs and symptoms, and recording data on the specially designed forms. Additionally, an "800" telephone number was available for APS and sentinel participants to call study staff with any questions about data collection procedures or client eligibility.

Data Collection, Receipt, and Management

Sentinel and APS data collection took place over an eight-week period. Starting in January 1996, all reporters in one or two counties started data collection each month, according to a preset schedule. Staggering reporting periods throughout this 12-month period (calendar year 1996) allowed the study to account for possible seasonal variations that might occur in elder abuse.

Sentinel data collection procedures were similar to APS agencies; however, sentinels were asked to forward reports of suspected cases of elder abuse to the NEAIS research staff as soon as possible after observing the suspected abuse. To encourage candid, confidential reporting, the designated coordinator in each sentinel agency did not review or edit forms completed by the individual sentinels. Sentinels also did not attempt to substantiate incidents of abuse. Sentinels, however, were carefully trained to screen out incidents that would not be supported as elder abuse or neglect. In contrast, all reports of suspected abuse received by the APS agencies were investigated and a determination of substantiation or nonsubstantiation made, as required by the laws of each state. It should be noted, however, that an APS agency's determination of nonsubstantiation of a report of abuse or neglect does

not mean conclusively that abuse or neglect did *not* happen. Rather, nonsubstantiation of a report can mean that the level of proof required by that state was not met, despite indications that abuse or neglect *may* have occurred.

NEAIS staff received and reviewed all submitted data collection forms for completeness and called the sending agency coordinators to discuss any missing or unclear data. Both APS and sentinel data forms required respondents to provide a brief narrative describing the maltreatment events. This maltreatment information was evaluated according to the study definitions and eligibility criteria, and reports that did not meet the study definitions were excluded from the database (e.g., victim lived in institutional setting; incident not based on common definitions).

Unduplication

The formal process of eliminating duplication in survey research data is called "unduplication." The NEAIS was interested in determining the number of new unduplicated elderly persons who were abused or neglected during 1996 in order to arrive at estimates of reported and unreported abuse and neglect. Sometimes more than one data form was received for the same maltreated elder, describing either the same or different abusive incidents. It was necessary to identify such duplicates and count each person only once for purposes of this study. Out of a total of 1,699 APS and sentinel reports, study staff identified 93 sets of genuine duplicates, resulting in 1,606 unduplicated reports (1,466 APS and 140 sentinel). Duplicate cases reported both to APS and sentinel agencies were removed from the sentinel data file, so that duplicated instances of abuse and neglect were counted as reports to APS. Duplicate sentinel reports were assigned to the sentinel agency that first sent in the form.

Obtaining National Estimates from the Study Data

The samples of agencies and sentinels who participated in the NEAIS were selected using scientific probability sampling methods to obtain a nationally representative sample. As a result, it is possible to make valid projections from the NEAIS data, to make national estimates of the numbers of elders who have been abused and neglected, and to describe their characteristics.

This estimation of national and subgroup totals and proportions is achieved by applying sample weights to each of the cases in the study. The weight applied to each elder abuse report can be thought of as indicating the number of cases nationally that are represented by the individual case in the study. By aggregating these sample weights for the relevant study cases, national and subgroup estimates are obtained, both of total numbers of elders, and their characteristics.

This methodology is routinely applied in national samples to measure social and economic issues. The Current Population Survey, which (among other things) produces the official U.S. monthly national estimates of unemployment and employment, is one well-known example. Another is the Health Interview Survey, which produces periodic national estimates for a wide range of health measures.

There were a number of steps involved in the process of developing weights for the NEAIS data. These are described in Chapter 3 of the full report, and in Appendix L.⁴

Interpreting Results in the Presence of Sampling Variability

A common technique used to present and interpret statistical data that are subject to sampling variability is through the use of confidence bands. A frequently used convention is to determine a 95 percent confidence band for each estimate. The statistical interpretation of a 95 percent confidence band is that, if such a band were constructed from all possible samples that might have been selected, 95 percent of such bands would contain the true answer.

If the confidence band for an estimate is wide, relative to the size of the estimate itself, then this indicates that there is considerable uncertainty as to what the true value actually is. If, however, the band is narrow, then there can be confidence that the estimate is close to the true answer. Thus, for example, consider an estimate that a certain population characteristic is at the 10 percent level. If the confidence band for this estimate ranges from 1 percent to 19 percent, we can have confidence that the true level is something below 20 percent, but cannot draw any other inference with confidence. If an

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⁴ The most important steps are the determination of overall probabilities of selection, calculation of nonresponse adjustments, and development of replicate weights. Unlike the sentinel records, there are no further sampling or nonresponse adjustments for the APS data, since all APS agencies in the sampled counties participated. One straightforward calculation is the annualization of the data. The staggering of different-sized counties throughout 1996 minimized the potential for seasonal affect to bias the estimates. Accordingly, this estimate of elder abuse over these two-month periods was transformed to an estimate for the full 1996-study year by multiplying the factor by six.

estimate of 10 percent is accompanied by a confidence band that ranges from 9 percent to 11 percent, then we can be confident that the true figure is little different from 10 percent.

Because the NEAIS sampled a relatively small number of counties, agencies, and sentinels, for many of the rarer characteristics described in this report the confidence bands are relatively wide (like in the first example given in the previous paragraph). When this has occurred, the estimates presented in the report are duly noted as having this characteristic.

Conclusions

The results of the National Elder Abuse Incidence Study (NEAIS) strongly confirm the validity of the "iceberg" theory of elder abuse that has been accepted in the aging research community for 20 years or more. The contribution the NEAIS has made to our understanding of the extent of elder abuse and neglect is graphically depicted by the large new middle area in Figure ES-1 below.

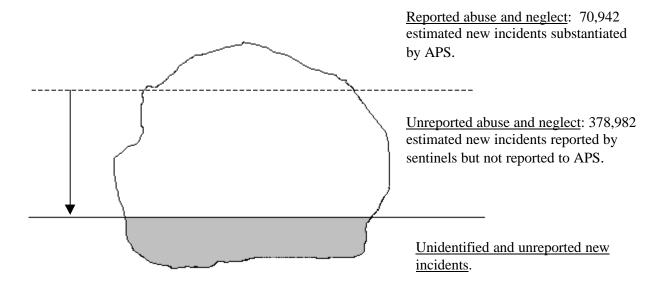


Figure ES-1.Iceberg theory showing NEAIS identified unreported abuse and neglect, excluding self-neglect

The NEAIS findings lead to the following conclusions:

- Domestic elder abuse and neglect is a significant problem. NEAIS research shows that about 450,000 unduplicated elders experienced abuse and neglect in domestic settings in 1996. More than five times as many of these incidents of abuse and neglect were unreported than were reported to and substantiated by APS agencies.⁵
- □ When elders who experienced only self-neglect are included with those that were abused and neglected, the number increases to 551,000 unduplicated elder persons in 1996. Almost four times as many of these incidents were unreported than were reported to and substantiated by APS agencies.⁶
- □ The NEAIS has measured a large and previously unidentified and unreported portion of elder abuse and neglect, and also has learned much about the characteristics of the victims and perpetrators of abuse and neglect.
- □ At the same time, it was not possible to identify and report on <u>all</u> previously hidden domestic elder abuse and neglect. Clearly, the NEAIS has not measured abuse, neglect, and self-neglect among those most isolated elders who do not leave their homes or who rarely come in contact with others in the community.
- □ Several of the characteristics of abused and neglected elderly persons are particularly worrisome and challenge us to prevent and intervene in this tragedy:
 - Our oldest elders (80 and over) are abused and neglected at two to three times their proportion of the elderly population.
 - Female elders are abused at a higher rate than males.
 - Almost half of substantiated abused and neglected elderly were not physically able to care for themselves.
 - In almost nine out of ten incidents of domestic elder abuse and neglect, the perpetrator is a family member. Adult children are responsible for almost half of elder abuse and neglect.
- □ Elderly self-neglect also is a problem, as evidenced by about 139,000 unduplicated reports (some of the self-neglecting elderly may also be counted as being abused and/or neglected). Most victims of self-neglect are unable to care for themselves and are confused. This is a difficult and troubling problem, which warrants further research and study.

⁵ Using precisely developed standard errors, the NEAIS estimates that as many as 688,948 or as few as 210,900 elder persons may have been abused and/or neglected in domestic settings in 1996.

⁶ When self-neglecting elders are added, the estimate range is that as many as 787,027 or as few as 314,995 elder persons may have been abused, neglected, and/or self-neglecting in domestic settings in 1996.

- □ Despite the study's identification of over five times as many unreported incidents of elder abuse and neglect as incidents that were reported to and substantiated by APS agencies, some professionals and researchers in the aging field may have expected this multiplier to be larger than NEAIS found. The NEAIS estimate may be lower than those expectations because:
 - Elder abuse and neglect are not as hidden and under-reported to APS agencies as they were at the time of earlier studies. Between 1986 and 1996, for example, official reports of abuse and neglect made to APS agencies throughout the country increased by 150 percent, while the total number of elderly persons aged 60 and over increased by only 10 percent. A much larger proportion of new incidents of domestic elder abuse and neglect was reported to official APS agencies in 1996 than was reported 10 years ago.
 - Still more of the unidentified and unreported area of the iceberg remains to be revealed, especially instances of abuse and neglect among seriously isolated elderly persons and those with little contact with community organizations.

Limitations of NEAIS

The NEAIS study design had some limitations that prevented it from making a definitive estimate of all incidents of elder abuse and neglect, including:

- The sentinel approach tends to cause a certain amount of "undercount" in the detection of domestic elder abuse because there are no community institutions in which most elders regularly assemble and from which sentinels can be chosen and elders observed (unlike schools in child abuse research).
- Sentinels cannot observe and report abuse and neglect of elders who are isolated and/or have no or very limited contact with any community organizations.
- Resource constraints for conducting the NEAIS limited the number of counties and sentinels sampled and the length of the reporting period. Consequently, the relatively small number of sentinel reports resulted in incidence estimates with wide confidence bands. Increasing the sample size and reporting period in future such studies would further improve the precision of incidence estimates through the calculation of narrower confidence bands.

Implications of Findings and Future Research Questions and Issues

The findings of the NEAIS suggest a number of important issues for policy development, practice, and training in addressing the problems of elder abuse, neglect, and self-neglect. Because states and localities historically have had responsibility for elder abuse reporting, investigation, and services, most of the implications are for state and local governments. These issues are discussed in the full report. Finally, the report raises a number of research questions and issues for researchers and service providers, including suggesting areas for future research of the incidence and nature of elder abuse and neglect.

Conclusion

The NEAIS has documented the existence of a previously unidentified and unreported stratum of elder abuse and neglect, thus confirming and advancing our understanding of the "iceberg" theory of elder abuse. NEAIS estimates that for every abused and/or neglected elder reported to and substantiated by APS, there are over five abused and/or neglected elders that are not reported. The study also documents similar patterns of underreporting of self-neglecting elders. NEAIS acknowledges that it did not measure all unreported abuse and neglect. Our collective challenge—as policy makers, service providers, advocates, researchers, and our society as a whole, is to utilize this information to better the lives of our elderly citizens.